

CCI Connect

February 2022



Welcome to the first newsletter for 2022.

Here we find ourselves in uncertain times yet again. But regardless of what is going on around us, CCI Support is still here and we are doing our best to support our members as best we can. I want to be clear CCI Support is a health organisation and therefore we support ALL members, vaccinated and unvaccinated. All of our staff are vaccinated, and some things may look a little different (eg no group member meetings face to face, instead held online), but where possible Social groups are still running. We are preferring Telehealth (video) and phone consults; however, we can also still do some face-to-face appointments (regardless of your vaccination status), but we may get creative how these are done.

We have some FANTASTIC news!! We introduce 2 new staff members this time, Luisa is the new Wellington Health and Wellness Facilitator, Luisa will be providing support (with a team of Volunteers we are hoping to recruit) for those in the greater Wellington region. She will be working 20 hours per week. It's so a awesome to finally have a dedicated staff member for this area.

In the Tauranga office we have Jemma, who is the amazing new Facilitator Assistant/Administrator. She is only in her second week, and I already know she will be an amazing asset to the team.

Sadly, we said goodbye to Kelsi and Tabitha over the Christmas break. Tabitha may still pop in from time to time – she didn't want to let us go. But we wish them well with their new adventures.

Please don't let the technological/remote way that we are working put you off contacting us, we are very much still here for you all, please contact us should you need to.

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Annabelle

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Office Hours

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Bay of Plenty

Hello there lovely members! I hope you had a lovely holiday season and got some sort of rest and/or time for yourself. It is important to practice our Pacing skills during this time as we can easily be carried away with it all. I managed to get to spend some precious time with my family enjoying the South Island and making some memories.

You can read all about it in the upcoming CCIS Newsletter blog. It's been a bit tricky navigating our way through the Covid restrictions, but we are hopeful to continue our coffee groups in Greerton (vaccinated) and Papamoa (non-vaccinated options). Karen and I are taking in turns to work from home and be in the office during this time. Which comes with its benefits and challenges.

We all need to learn to adapt in some way, but I suppose staying safe and being kind to each other during these times is the most important thing. Its lovely to see you connecting with each other on our Facebook page and to have you join us for our Member Meetings. I will be taking the next one for the first time in March so am a little bit nervous, but I know you will be kind to me! We have had so many new members recently, please take time to welcome them and maybe form some social connections, if you are in the same area.

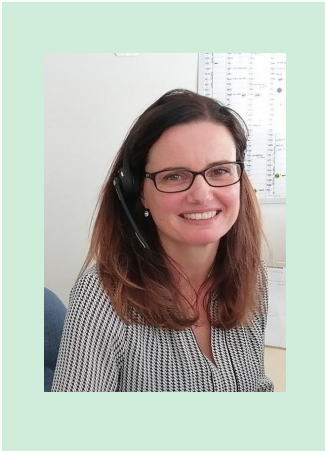
We have also continued our support to our Lakes members since Tabitha left and are looking for volunteers to run social/coffee groups in the Rotorua and Whakatane area.

If you are interested or already have a group please let us know. Lastly, the Towards Wellness Online Hub/Program is in its editing stage and hopefully be with us soon, we will keep you posted.

Till next time, take care xx

Karen

Health and Wellness Facilitator



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9am til 2pm

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National – Based in Tauranga

Hello to all our lovely members, I hope you had a wonderful and restful Christmas and New Year. I had a lovely Christmas break with my two sons. We enjoyed spending time relaxing at home and making the most of our beautiful beaches here in Tauranga. I did however have an unlucky encounter with the famous Mount Maulers, which was very unpleasant to say the least but did not stop me enjoying the beach.

Wow, the weather this summer has been incredible! The bright sunny days and clear blue skies have been great, but the intensity of the heat has been challenging to say the least! The tips from the last member meeting in December 'Managing the Festive Season' proved very useful -especially the ice packs at bedtime and fan facing the window to draw out hot air from the room.

The challenges of 2021 continue into 2022 with COVID-19, Delta and Omicron now in the community and the challenges and stress this presents to us all. With the ever-changing dynamics of life during this time, I was recently reminded how important it is to take good care of oneself and family as we prepare for the outbreak, especially where there is a possibility of isolating for a period. While this is not uncommon for us with chronic illnesses to be isolating, we may also have family members isolating with us at the same time. Some of my lovely members have shared with me their plans with family, friends, neighbours and local community to help with essential supplies, such as food and medicine and staying connected with others online scheduling regular catch ups and check ins. Some great ideas here to help get us all through these times.

I look forward to connecting with you all this year, over the phone, online and in person where I can (Tauranga). Please contact us, if you need support, more information or resources and remember to take really good care of yourselves.

Nga Mihi

Karen -Wellness Facilitator Tauranga and Nationwide

News from the Wellington Region

Kia Ora,

My name is Luisa and I am your Health and Wellness facilitator in the Wellington Region. I am really looking forward to getting to know you all and walking along side you in this journey. I'm a mum of two and have been living in Wellington for 13 years (and absolutely love it). I have a background in psychology with clinical and health, and I'm currently on my second year of Masters in Health Psychology. I am very passionate about health, wellness, and understanding how biological, psychological, and social/cultural factors can influence health. I believe in empowering and supporting people through connection and empathy, and view health as a holistic process that is not only physical but psychological and spiritual. Health is experienced differently by all of us, with every person being their own universe with different individual needs. I am here to listen and support you through your own health journey in whichever way I can.

I am extremely excited to be a part of the CCIS team, learn more about my role, and continue to expand my knowledge further.



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Health and Wellness Facilitator

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From the Waikato Desk



Tracey

Health and Wellness Facilitator

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Regional Update – Waikato

Kia Ora and Welcome to 2022. I hope the year has started well for you.

As I write this, we have had some beautiful rain to quench our parched land, however, inevitably, the humidity follows when the sun comes out again. I hope you are all managing ok. If you are struggling, have a look at our December topic notes where I discussed ways to keep cool.

Well, COVID continues to rule our lives here at CCIS with social and in person members meetings being postponed for now. We will review this month by month as to when we start our meetings again in person. A great thing to have come from this though s our numbers are increasing at our online meetings. It was great to see more of my Waikato people there this week.

The year has started very busy, with record numbers of new clients joining our organization. I am slowing attending to my welfare checks with you all, but please remember to be in touch if you have any questions and concerns. I look forward to connecting with you this year.

Nga mihi

Tracey Larsen.





Useful Links

Reliable information on COVID-19

For all your questions around COVID-19 from Understanding the traffic light system to financial support
<https://covid19.govt.nz/>

Booking a Covid-19 Vaccination

<https://bookmyvaccine.covid19.health.nz/>

BOOK OVER THE PHONE
 You can call the COVID Vaccination Healthline
 8am–8pm, 7 days a week.
0800 28 29 26

Time In The Line

Check on available Covid 19 vaccination appointments.

Dr Ros Vallings' Vaccine Recommendations

- Covid-19 can kill, therefore vaccination wise
- Those with ME/CFS may be "self-protected" by immune activation, but no guarantee
- Vaccine is not "live", therefore risk of serious reaction is less
- Getting Covid-19 may worsen ME/CFS (serious relapse)
- Choose time for vaccine when at one's "best"
- Allow 2-3 days before and after vaccination for rest
- Be prepared for "reaction" (paracetamol, antihistamine, prednisone)
- Stay at facility for up to an hour



Mental Health Foundation

Looking after mental health and wellbeing during COVID-19

<https://www.mentalhealth.org.nz/get-help/covid-19/>

Anxiety around COVID-19

Care for your Coronavirus Anxiety by Shine Tool kit – Resources for anxiety and your mental health in a global climate of uncertainty.

[https://www.virusanxiety.com/?](https://www.virusanxiety.com/?fbclid=IwAR2BZPuM9wJunh528RErEZHyry92PBdzk5aMNLiHf)

[fbclid=IwAR2BZPuM9wJunh528RErEZHyry92PBdzk5aMNLiHf](https://www.virusanxiety.com/?fbclid=IwAR2BZPuM9wJunh528RErEZHyry92PBdzk5aMNLiHf)

Anzmes Survey

Thank you to our clients who participated in our initial survey, ANZMES then followed on with a larger scale and below are the findings.

At the request of the ME/CFS community, ANZMES has issued a survey relating to reactions experienced by the community to the COVID-19 Pfizer BioNTech vaccine. ANZMES also sought to ascertain prevalence of Long COVID and COVID-19 infection in the community. The opportunity was also utilised for respondents to express interest in participating in a potential fractionated dosing trial.

Vaccine effect on state of illness/wellness for 359 respondents

- 137 (38.1%) experienced no change/stay the same
 - 118 (32.9%) temporarily worsened but have returned to baseline
 - 71 (19.8%) worsened and not returned to baseline – relapsed
 - 22 (6.1%) improved
 - 11 (3.1%) worsened beyond anything experienced in illness to date – severe relapse
- 289 respondents did not have any new symptoms that they could attribute to the vaccine.

52 stated that they had new symptoms that they could attribute to the vaccine. These symptoms tended to be over-activation of the immune response, e.g. sore throat, swollen neck glands, allergy reactions. Of these 52 – 4 individuals have gastrointestinal issues, 2 experienced more fatigue whilst 1 indicated improved energy.



Monthly Members Meetings.

For March the focus of our Monthly Members Meeting is Breathing and Mindfulness
For April it is Restorative Movement and Mindfulness

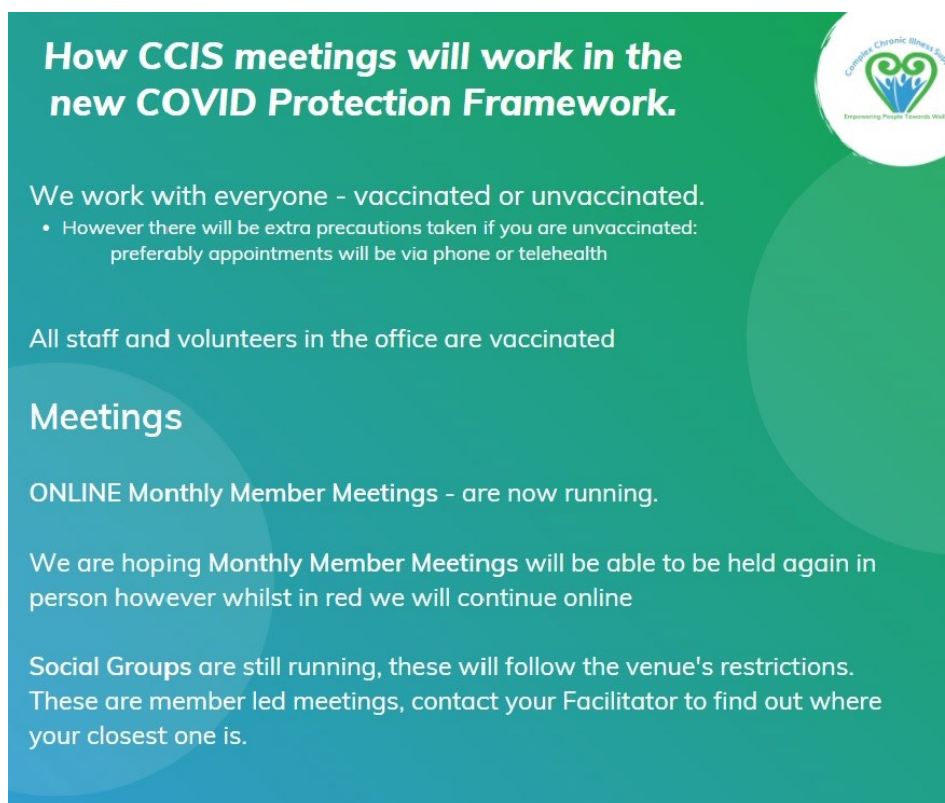
All MONTHLY MEMBER MEETINGS WILL BE ONLINE FOR THE REST OF 2022 DUE TO COVID RESTRICTIONS.

Online Members Meeting

Is for all our members who want to attend a monthly meeting but do not have the extra energy to leave their homes.

Just contact your Facilitator to get a link to join.

You just click the link on computer or smart phone and you can easily join with us.



How CCIS meetings will work in the new COVID Protection Framework.

We work with everyone - vaccinated or unvaccinated.

- However there will be extra precautions taken if you are unvaccinated: preferably appointments will be via phone or telehealth

All staff and volunteers in the office are vaccinated

Meetings

ONLINE Monthly Member Meetings - are now running.

We are hoping Monthly Member Meetings will be able to be held again in person however whilst in red we will continue online

Social Groups are still running, these will follow the venue's restrictions. These are member led meetings, contact your Facilitator to find out where your closest one is.

Counselling available

Rachel, our 2nd year counselling student in Tauranga is continuing with us. These sessions are free. This counselling will be offered for all ages and it will be provided in a strictly confidential environment. Please contact Karen or Annabelle for enquires.
wbop@ccisupport.org.nz

Social Groups.

These are casual meetings with no set subject or discussion points and are essentially member run. The Kaupapa of the groups are to empower connections with each other, learning helpful information for management, sharing, laughing and appropriate friendships. Finding friends who experience what you experience is so very important. It is difficult to keep your friends when you live with a condition that means you can't go to social events when you want to. So, finding a person who understands and "gets it" can be so empowering and helpful.

Please note we will advise members of any cancellations due to Covid-19 alert levels. **These only run in LEVEL ONE!**

Greerton Coffee Group

Venue: Greerton Mitre 10 Mega (3rd Wed of each month) 10.30am

Papamoa Coffee Group

Venue: Double Teaspoons (1st Wednesday of every month) Papamoa Plaza, 10.30am

Young at Hearts Social Group

ON HOLD— due to no meetings being held at Fraser St

EBOP Coffee Catchup

4th Tuesday of the month at 10.30am

Café Coco—10 Richardson Street, Whakatane

Waikato Social Groups

ON HOLD—due to COVID

Tracey can be contacted on waikato@ccisupport.org.nz or phone/Text 022 154 7076



Group Touchstones

Contribution to the group is by invitation, not by demand

Keep discussion flowing within the group

Withhold off-topic questions for individual participants until after the session

Speak your Truth in ways that respect other peoples Truth.

Speaking one's truth does not mean interpreting, correcting, or debating what others say

Refrain from fixing, saving, advising, or correcting each other

Respond to others with open questions.

Help 'hear each other into deeper speech' when doing activities

Be curious and turn to wonder.

If you feel judgmental or defensive, ask yourself 'I wonder what brought this person to his or her belief?'

Moderate patterns

Some of us are more confident to speak than others.

If you contribute often, allow space for others to contribute. If you are reserved, take opportunities to share

Watch and Observe....

Although we learn from others ideas and thoughts, we also learn from our own reactions and responses.

Honor confidentiality

Safety is built when we can trust that our words will remain with those with whom we choose to share, and will never be passed on to others without our explicit permission

Know it is possible to leave this room with whatever you needed

Most 'aha moments' occur between sessions

Refrain from sharing information about products and events until after the session

Refrain from using cellphones, unless for emergency

Adapted from the Centre of Courage and Renewal Touchstones, as used in the Towards Wellness Programme



FEBRUARY MEMBERS MEETING

Stress

Today we will cover

- ♦ What is stress?
- ♦ What happens in the body when it is stressed?
- ♦ The role of the Autonomic Nervous System
- ♦ Stress and ME/CFS/FM
- ♦ The process of the stress response
- ♦ Symptoms of stress
- ♦ The freeze response
- ♦ Strategies for managing stress

What is Stress?

The Definition of Stress

Oxford Dictionary states:

Pressure or worry caused by the problems in someone's life

Wikipedia states:

Either physiological, biological, or psychological, is an organism's response to a stressor such as an environmental condition. Stress is the body's method of reacting to a condition such as a threat, challenge, physical or psychological barrier.

Another definition is offered by Walt Schafer:

Stress is arousal of mind and body response to demands made upon them (Walt Schafer 2000)

Schafer also comments that stress is a universal feature of life and arousal is an inevitable part of living. We constantly think, feel and act with some degree of arousal. Stress cannot and should not be avoided. Rather, it is to be contained, managed and directed.

Stressors are ever present and adapting to change a continuous process. Most of the time people respond to the demands with ease and familiarity. Stressors are a fact of life often with no ill effect. But adjustment to changes can take a toll and cause wear and tear on the mind and body. Physical upset or emotional turmoil often results. When this happens stress become

Three types of stress

1) Positive Stress

Helps when responding to emergencies or preparing deadlines

Useful when performing well under pressure

Can add zest and variety to daily life

Can help when pushing beyond comfort limits and can help with achieving personal growth

2) Distress

Occurs when arousal is too high

3) Neustress

This is a term given to when one responds to internal and external demands

Mind and body arousal occurs but there is little impact from these demands in one way or another– meaning the stress is neutral-neither particularly helpful nor harmful

"The challenge is to identify your own zone of positive stress and to maintain a perspective and lifestyle that will enable you to stay within that zone most of the time"

(Schafer 2000)

What happens in the body when it is stressed?

The role of the Autonomic Nervous System (ANS)

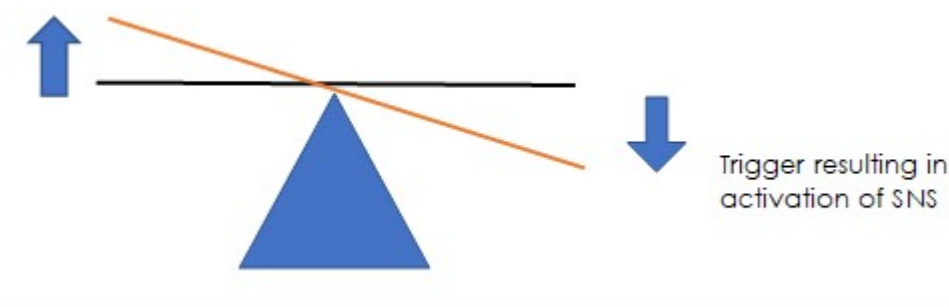
The ANS is made up of the Sympathetic Nervous System (SNS) and the Parasympathetic Nervous System (PNS).

The ANS is responsible for regulating and maintaining a constant internal temperature, regulating breathing patterns, keeping heart rate and blood pressure steady. It is also involved in pupil dilation, sexual arousal and excretion.

It functions automatically; meaning that we do not have to think about it at all, it just does what it needs to do.... Isn't nature magical!

When the SNS is aroused by stress, the fight or flight stress response occurs and can be likened to the accelerator of a car.

The PNS calms the body back to a balance state after the stressor or trigger has gone or as we get used to the new situation and adjust to change– often known as the rest and digest repair system and acts much like the brakes of a car.



Stress and ME/CFS/FM

With ME/CFS/FM research indicated that there is a dysfunction within the Autonomic Nervous System (ANS)

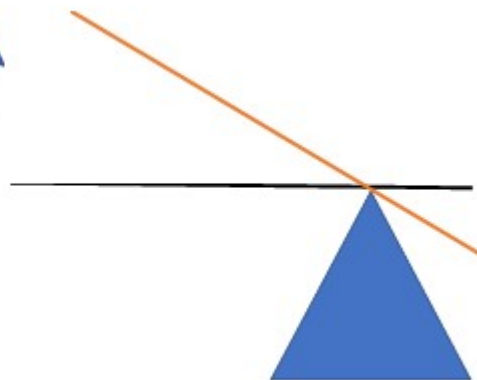
The activity of the fight or flight (sympathetic nervous system) response is increased and/or that the activity of the 'rest and digest' (parasympathetic nervous system) response is decreased in ME/CFS and FM patients.

It further suggested , "that an overactive stress response system has triggered the neuroinflammation in fibromyalgia, chronic fatigue (ME/CFS) and similar disorders".

<https://www.healthrising.org/blog/2020/06/05/fight-flight-neuroinflammation-fibromyalgia-chronic-fatigue-syndrome/>

A malfunctioning
point for SNS
much more
meaning
smaller trigger
much longer
SNS response

Raised SNS response



tioning ANS
that the pivot
and PNS is
sensitive,
that a much
ger results in a
and higher
response.

Let's back track for a moment to positive stress, mentioned above. Positive is all very well for the healthy living in this world, however for those living with ME/CFS/FM, the malfunctioning ANS could mean that simply standing up could trigger a stress response. Typically over exertion of activity is usually what causes a stress response that leads to post exertion malaise, flare up in pain or relapse, but so too can an emotional response of loss, grief, sadness, and even one of excitability can cause a stress response that may exacerbate symptoms.

Typically anxiety and depression are experienced by those with ME/CFS/FM which also continually exacerbate the SNS and stops the PSN from activating to allow for relaxation, rest and repair.

Mental and emotional triggers also equal stress response.

So too, a physical injury, or pushing beyond energy limits can cause a stress response in those with ME/CFS/FB.

Process of the Stress Response

The following example demonstrates how a stressor can trigger a wide ranging response involving all of our body systems all without us even being consciously aware!

The Nervous System (the brain and the spinal cord) registers a stressful situation, perhaps for example you get a fright, maybe there was a loud unexpected bang from outside that made you jump. Information is sent from the external sensory nerves to the brain, which is your body's command center.

The brain activates the sympathetic nervous system to prepare for the 'fight or flight' response.

The nerves then send the message from the nervous system to the endocrine system. The endocrine system consists of glands which produce hormones and chemicals in response to this message that 'there is an emergency'. These hormones are adrenaline and cortisol and are instantaneously released into the blood stream.

Adrenaline's message is 'there is danger!' gives us a burst of energy so that we can fight or run away.

Cortisol's message is 'there's a famine!' so the body responds by storing fat and breaking down muscle tissue for extra energy.

These hormones are then carried through the cardiovascular system for fight or flight. The response here is of an increase in heartbeat, pulse rate and blood pressure.

Blood is then pushed to the outer extremities and to the muscular system for fight or flight. The Integumentary System, which comprises of the skin, is also affected by a slight rise in temperature and producing sweat.

A message is also sent to the Respiratory System which is the lungs. The message asks the body to take shallow breaths because this sends more oxygen to the brain for a shorter time to increase alertness. Sight, hearing and other senses become sharper.

Adrenaline sends a message to the pancreas to release glucagon, which acts to raise blood sugar levels, giving us more energy and increased alertness.

The Skeletal System also receives the message to release nutrients and fat in order to supply energy to vital parts of the body.

Symptoms of Stress

So let's have a look at what happens when one is in a long term, chronically stressed state.

Long term shallow breathing results in lower amounts of immune cells.

The body is then susceptible to contracting acute illnesses, and prolonging healing times. Shallow breathing can turn into panic attacks, cause dry mouth and fatigue, aggravate respiratory problems, and is a precursor for cardiovascular issues.

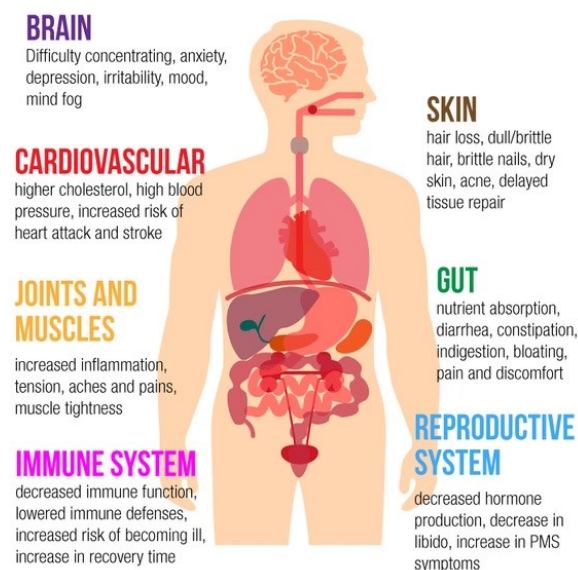
When we breathe with our chests, we use the muscles in our shoulders, necks, and chests to expand our lungs, which can result in neck and shoulder pain and headaches.

Persistent surges of adrenaline can create imbalances in blood sugar levels, which can lead to Hypoglycaemia, damaged blood vessels, increased blood pressure, and an increased risk of heart attacks or stroke. It can also result in anxiety, weight gain, headaches, and insomnia.

Sight, hearing, and other senses become hypersensitive.

The immune system, digestive system, urinary, and reproductive systems can be significantly impaired and possibly can shut down completely.

HOW STRESS AFFECTS THE BODY



Do you have digestive issues? Could stress be the cause?

Other Physical symptoms include:

- *Aches and pains*
- *Chest pain or a feeling like your heart is racing*
- *Exhaustion or trouble sleeping*
- *Headaches, dizziness or shaking*
- *Brain fog & poor concentration*
- *Accelerated speech*
- *High blood pressure*
- *Muscle tension – tight shoulders and/or jaw clenching*
- *Stomach or digestive problems.*
- *Trouble having sex*
- *Weakened immune system*
- *Emotional and mental symptoms*

Stress-related disorders

- *Migraines*
- *Psoriasis*
- *Colitis*
- *Arthritis*
- *Noncardiac chest pain*

- *Anxiety or irritability*
- *Depression*
- *Panic attacks*
- *Sadness.*
- *Drinking alcohol too much or too often.*
- *Gambling.*
- *Overeating or developing an eating disorder.*
- *Participating compulsively in sex, shopping or internet browsing.*
- *Smoking.*
- *Using drugs.*

Chronic stress can lead to maladaptive behaviours that can further induce a stress response, such as:

- *Dizziness*
- *High Blood Pressure*
- *Gastritis*
- *Ulcers*
- *Panic Attacks*

The Freeze Response

In a freeze state, the PNS and SNS engage at the same time. This is like pressing the accelerator and brake in the car simultaneously. Freeze is immobility coupled with fear, which happens when the level of activation reaches a certain physiological threshold. The freeze state is when there is already significant SNS charge and then the PNS also activates and acts like a circuit breaker that shuts down the physiology when it is overloaded. This can all happen in a split second and often there are no symptoms of SNS arousal first.

Characteristics of the nervous system in freeze response can be seen when:

- *One shut's down*
- *Feels sudden tiredness*
- *Blankness*
- *Can't think straight*
- *Has numbness in the body*
- *Feeling of paralysis or stuck-ness in the limbs and/or expression on the face*
- *Confusion*
- *Apathy*
- *Indecisiveness*
- *Procrastination*
- *Hyperarousal*
- *In some cases – disassociation, may result.*

Sound familiar?

Some Strategies to Manage Stress

The following from The Healthy Work Place: Stress First Aid Kit, is worth mentioning.

“One of the difficulties is that as humans, our heads take over and we create further stress by telling ourselves enticing stories of how awful something was or could be... we worry about things that haven't happened. Our heads, far from being the central control unit, are more like the central processing unit, which takes in signals from the around the body. So, the key to effective stress management is working with the body, not just the mindset. It is virtually impossible to use the head to talk yourself out of a stress response”

How true is this last sentence?!!

How often do we forget to put into practice good techniques when stressed?

I can put my hand up too!!

What I do notice though, is tension in my body.

The above quote suggests that by relaxing the body, your mind and central nervous system will follow.

Thinking will become clearer too.

Limit or avoid alcohol and caffeine – not only dehydrating but can also activate SNS and producing a stress response.



BREATHE!

Breathing is the only way we can consciously affect our ANS. Diaphragmatic breathing is excellence in helping circulate blood and bring more oxygen into the blood. An excellent way to help calm an accelerated heart rate and also manage anxiety



CONSCIOUSLY RELAX – If you can manage this pose, try it for 10 minutes several times a day to bring calm to the ANS. This also helps to realign the hips, spine and shoulders (make sure both toes are tucked well into the corner of the wall and floor).

Maintain healthy dietary habit, sleep habits,

Practice gratitude and maintain a positive outlook

Adopting the right attitude can convert a negative stress into a positive one.

Accept that you can't control everything. Find ways to let go of worry about situations you cannot change.

Learn to say "no" to additional responsibilities when you are too busy or stressed

Stay connected with people who keep you calm, make you happy, provide emotional support and help you with practical things. A friend, family member or neighbour can become a good listener or share responsibilities so that stress doesn't become overwhelming.

Research Summary – Are people with ME/CFS at higher risk of complications from COVID infection?

The SARS-CoV-2 receptor angiotensin-converting enzyme 2 (ACE2) in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: analysis of high-throughput epigenetic and gene expression studies.

Are people with ME/CFS at higher risk of complications from COVID infection? A [recent publication by Malato et al.](#) carried out using ME/CFS patients from Germany has shown that this could be the case.

Due to the complex nature of this paper, we have divided this research review into sections, where a basic understanding can be gained in the first section, and a deeper scientific understanding can be gained from reading on.

WHAT ARE THE BASICS IN THIS STUDY?

- The etiology (the cause) of ME/CFS remains largely unknown, but many patients report an infection which triggers the onsets.
- There is growing evidence of the overlap in symptoms of ME/CFS and long-COVID, such as persisting fatigue and post-exertional malaise (PEM) leading to more studies about the two conditions.
- Evolving technologies have allowed more detailed research into gene expressions in diseases, which produces large amounts of data.
- An unbalance in certain enzymes in the body can lead to different diseases and also increase the potential for “catching” viruses, such as COVID-19.
- This study looked at one particular enzyme, ACE2, which is the key receptor enzyme used by COVID-19 to enter human cells.
- The key finding of this study was a decreased gene expression of ACE2 in patients with ME/CFS compared to healthy controls, which could mean a could be at a higher risk of developing severe symptoms of COVID-19.

IT IS HOPED THAT THIS STUDY COULD HELP TO IMPROVE THE UNDERSTANDING OF THE HEALTH RISK IMPOSED BY THE COVID-19 VIRUS WHEN INFECTING PATIENTS AFFECTED BY ME/CFS.

WHAT IS THE BACKGROUND?

Previous studies on ME/CFS have shown that patients have different gene expressions compared to healthy controls ([Kerr, 2008](#); [Almenar-Pérez et al., 2019](#); [Dibble et al., 2020](#)), however, it is not known whether these changes affect certain key enzymes in the body.

This paper looked at two enzymes called ACE and ACE2 (human angiotensin-converting enzymes). The enzyme ACE2 is of significant importance due to it being found to be the **main receptor** used by the virus **COVID-19 (SARS-CoV2)** to enter human cells.

There is a complex relationship between these two enzymes and COVID-19:

1. The failure in the body to balance the ratio between the amount of these two enzymes ACE and ACE2 can lead to hypertension and cardiovascular diseases, which is also thought to play a key part in COVID-19.

It has also been found that ACE2-deficient individuals also seem to be at a higher risk of COVID-19, because viral entry typically induces a downregulation of this enzyme, which ultimately affects its balance with ACE.

Patients with ME/CFS are often found to have an unbalanced immune system. Previous studies have suggested that the ACE enzyme could provide a potential biomarker with the ACE enzyme being elevated in 80% of patients ([Lieberman and Bell, 1993](#)). This study looked at increasing our knowledge of the role of the ACE2 enzyme as little is known about its role in ME/CFS to date.

WHAT DO SOME OF THE KEY SCIENTIFIC TERMS MEAN IN THIS PAPER?

- **Gene expression** is the amount of **transcription** of a gene that can be found in a biological sample at the time of sample collection.
- **Gene expression** is affected by both **genetic variation** and **epigenetic modifications**.
- **Genetic variation** relates to changes in the **nucleotide sequence** of the gene.
- **Epigenetic modifications** refer to all the additional changes that occurs from the **translation of the encoding nucleotide sequence** into the respective encoded protein.

DNA methylation is an **epigenetic modification** in which a chemical called **methyl** is added to pairs of **cytosine/guanine nucleotides** present along the human genome.

DNA methylation is of particular importance. The pairs of cytosine/guanine in the adjacent nucleotide sequence of a gene makes the opening of the respective **chromosomes** more difficult for the respective gene translation. Hence, low methylation levels (hypomethylation) of these pairs typically indicate an easiness to express a gene by a given cell, whilst high methylation levels (hypermethylation) pairs indicate the opposite.

Previous studies investigated the expression and DNA methylation of all the genes present in the human genome in patients with ME/CFS and healthy controls. They found that, when compared to healthy controls, patients have **altered expression of different genes and methylation** levels of these cytosine/guanine pairs located in specific positions of the genome ([de Vega et al., 2014](#); [Trivedi et al., 2018](#); [Helliwell et al., 2020](#)).

However, we do not know whether these alterations could include the **ACE2 enzyme**, which is the receptor used by SARS-CoV2 to enter the human cells. In particular, low levels of ACE2 in patients could imply a higher risk of developing severe symptoms of COVID-19.

WHAT WAS INVESTIGATED?

The study used **DNA methylation** and **gene expression** data from published studies and focused their analysis on ACE2 and its related enzyme, ACE.

The study aimed to compare the gene expression and DNA methylation levels of these two enzymes between patients and healthy controls.

To complement the analysis, they collected samples from German women with ME/CFS and matched healthy controls and measured the levels of ACE and ACE2 in these samples.

WHAT ARE THE MAIN FINDINGS OF THIS STUDY?

The study found increased DNA methylation levels of a pair of cytosine/guanine adjacent to the nucleotide sequence in ACE2 using published data from 4 DNA methylation studies. This suggested an increased expression of ACE2.

However, when the research group conducted a joint analysis of data from published gene expression studies, they found a decreased gene expression of ACE2 in patients with ME/CFS than in healthy controls. Along with similar evidence in data from the German cohort where many samples from patients had an ACE2 expression below the detection level.

WHAT ARE THE IMPLICATIONS OF THIS RESEARCH?

If patients with ME/CFS have a decreased expression of ACE2, then they could be at a higher risk of developing severe symptoms of COVID-19. As a possible implication, patients with ME/CFS alongside patients of other diseases but with comorbidities affecting ACE2 levels could be considered a priority group for vaccination.

However, caution should be taken with these results as vaccination could trigger ME/CFS and it could also aggravate the ME/CFS-related symptoms in a natural infection by SARS-CoV-2.

More about the ME Association communities experience on vaccination can be found [here](#).

Furthermore, as the authors comments, that the findings of this study could be improve with making data more publicly available along investigations such as this study.

"It could also promote collaboration among researchers, and to make science open to everyone, specifically, when it is funded by taxpayers and charities. Data sharing is also essential to cut down the costs of research by sharing resources among the research community. Reducing the costs of research by sharing limited resources is particularly important for the underfunded ME/CFS research field, as alluded above."

WHAT ARE THE NEXT STEPS FROM THE FINDINGS IN THIS RESEARCH?

The next step is to perform similar analysis on other receptors used by SARS-CoV-2 to invade human cells.

Examples of these alternative receptors are: (i) the human transmembrane protease serine 2 (TMPRSS2); (ii) the A disintegrin and metallopeptidase domain 17 protein (ADAM17) recognized by the immune system as a stress-response signal, and (iii) Dipeptidyl peptidase-4 (DPP4) known to be the main receptor for the Middle East respiratory syndrome-related coronavirus.

The first author of this paper and PhD student João Malato might perform this follow-up analysis. Given that the study was based on analysis on data from peripheral blood mononuclear cells, it would be also interesting to study different cell types, namely, those mainly targeted by the virus (e.g., pulmonary epithelial and endothelial cells).

WHAT ARE THE LIMITATIONS OF THE FINDINGS IN THIS RESEARCH?

The authors from the study say:

"This was an opportunistic study and, as such, we could only analyse data derived from peripheral blood mononuclear cells (e.g., T and B cells, monocytes, macrophages, and dendritic cells) – because they are easily collected. We should emphasize these cells are not the primary targets of SARS-CoV-2 and therefore, our findings may not reflect what is happening in cells of the lungs and other organs affecting by a SARS-CoV2 infection. Another limitation is that most of published gene expression studies did not deposit their data in any public database. Therefore, we could not analyse data from many different studies that could strengthen our findings."

WHAT ARE THE AUTHORS CONNECTIONS TO ME/CFS?

"I was the Portuguese representative and a member of the managing committee in the EU-ROMENE network. I was also working as an Assistant Professor at the London School of Hygiene & Tropical when I started a close collaboration with the [CureME](#) group led by Dr Eliana Lacerda and Luis Nacul and the United Kingdom ME/CFS biobank. I am actively collaborating with Prof Carmen Scheibenbogen and Dr Eliana Lacerda in a project about [EBV immune responses](#) funded by ME Research UK. I am also collaborating with Dr Francisco Westermeyer in [endothelial function in ME/CFS](#). I also started a ME/CFS-related project on the impact of viral infections on genes related to circadian rhythm. More information about this is available on the research group's [webpage](#)."

Book Review

The Body Keeps The Score By Dr Bessel Van Der Kolk

This a poignant book about how trauma reshapes the brain and the body, compromising the capacity for pleasure, engagement, self control, and trust. The book explores different treatments from neurofeedback and meditation, to drama and yoga, all which aim to create new paths of recovery by activating the brain's natural plasticity.

The book highlights the power of relationships, and the ability for those to hurt and heal.



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Gluten-Free Muesli by Chelsea Winter

Ingredients

DRY INGREDIENTS

2½ cups sliced almonds
2 cups sunflower seeds
2 cups buckwheat groats
2 cups desiccated coconut
2 cups shredded coconut or coconut chips
2 1/2 cups walnuts, roughly chopped
1 1/2 cups pumpkin seeds
1 cup sesame seeds

DRIED FRUIT

2 1/2 cups dried apricots, chopped (Sulphur -Free Apricots are available)
2 1/2 cups dates, chopped (not the fancy ones – or use other dried fruit such as sultanas)

WET INGREDIENTS

1/3 cup almond butter
1/3 cup honey (or use maple syrup)
1/4 cup maple syrup
1 tsp vanilla extract (optional)
1/2 tsp salt

To make

Preheat the oven to 180°C regular bake and get your biggest oven tray ready (or a huge metal roasting dish if you have one). You may have to cook this in two batches.

If your roasting dish has sides, you can use this to both toast the dry ingredients and mix the final muesli. Or, use a huge mixing bowl to combine things at the end.

Add the dry ingredients to the roasting dish/bowl and mix well to combine. Transfer to the oven tray if necessary and bake until you see the top and edges going slightly golden (5–10 minutes). Give it a stir, and however long it took to cook the first time, keep baking in those intervals, stirring after each time, until the whole lot is a little toasty – about 3-4 times usually does it. The coconut chips will brown first, so make you sure keep stirring it so it doesn't burn.

If necessary, tip it back into the mixing bowl. Add the dried fruit and mix to combine.

Heat the wet ingredients in a small saucepan until melted, then pour over the muesli and stir together to coat evenly.

Leave the muesli to cool completely, then transfer to airtight containers or jars. A jar of it looks very beautiful on the kitchen bench, and the rest is best stored in the fridge so that the oil in the nuts doesn't go rancid in warm weather.

Serve with nut milk, stewed or fresh fruit, Chia Pudding (see recipe in Superfood) and yoghurt or coconut yoghurt. Stewed or canned black Doris plums are my favourite, or homemade stewed apple. And fresh berries are in season!

I am constantly on the hunt for healthy breakfast options that are suitable for my diet and entice me to eat breakfast, as I am often not hungry first thing in the morning but starving by 10am and lacking in energy. I decided to try out Chelsea Winter's Gluten-Free Muesli from her latest cookbook Superfood I received as a Christmas present and have to say this is the most delicious home-made muesli I have tasted. I was however a bit alarmed at the amount of ingredients, but this recipe makes a huge amount, that can last for weeks in an airtight container. I serve mine with defrosted frozen berries and dairy free yoghurt. If one can tolerate oats, a couple of handfuls can be added and/or addition of pre-puffed grains.

Karen Maxwell Wellness Facilitator



How CCIS appointments will work in the new COVID Protection Framework.



Appointments with Facilitators

- Available to everyone, if you have a local facilitator then you can have these Face to Face too.

Before all Face to Face meetings

- You will be asked some COVID clearance questions
- Masks are mandatory for all face to face meetings
- 1 metre distancing will be observed for everyone
- Scan or sign in for all face to face meetings
Facilitators will have a QR code available for you.
- If you are unvaccinated, these may be at an alternative venue

Fraser Street Head Office

- Visits to the offices of CCIS are by appointment only.
- Due to sharing the offices with immunocompromised agencies, only vaccinated people are allowed entry to the Fraser St offices at this time .
You will need to show your vaccine pass for verification for appointments in this office.



It's important for planning, it's important for funding and it's it important we get the service right for you. Please contact Miranda on info@ccisupport.org.nz with any service feedback.

Thanks so much!! The team at CCI Support.



FACEBOOK: Just a reminder, for paid members, we have an online members [Facebook page](#). Keep up with the latest research, make friends and support each other.

Contact your Field Officer for more details.

REMEMBER: It is important to get a sensible amount of unfiltered light directly on the skin each day (for vitamin D absorption and melatonin release).



DONATIONS: We want to thank all those people who donate time and/or money to CCIS, on top of their annual subs. As a charitable organisation, we rely solely on donations, grants and subscriptions in order to provide the support for our clients. So every \$ counts. We are registered with IRD as being for charitable purposes, so donations are tax deductible over \$5.00. Dona-

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Complex Chronic Illness Support Inc. is a charitable organisation that was set up in 1981 in the Bay of Plenty region to support, connect, advocate and educate people diagnosed with Complex Chronic illnesses to improve the quality of their lives. We provide this service across the Bay of Plenty and Waikato and Greater Wellington Region.

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